



Australian Government

Cancer Australia

Cancer support groups: A guide for peer facilitators



**Cancer support groups:
A guide for peer facilitators**

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ISBN: 1-74186-812-2

Online ISBN: 1-74186-813-0

Publications Approval Number: P3-4834

Cancer Australia (2009). *Cancer support groups: A guide for peer facilitators*, Cancer Australia: Canberra.

This document is available at: www.canceraustralia.gov.au

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Acknowledgments

These publications were developed by the Health Issues Centre for Cancer Australia. Cancer Australia acknowledges the work of the Health Issues Centre and its staff—Ms Vanessa Lynne, Dr Tere Dawson, Dr Nicola Bruce and Mr Tony McBride—in developing these consumer resources.

We would like to thank the project Steering Committee who provided valuable feedback during the development of this resource. Members of the Steering Committee included: Professor Ian Olver, Ms Susan Hanson, Ms Doreen Akkerman, Dr Anne Atkinson, Mr William Darbishire, Mrs Juli Ferguson, Mr John Stubbs, Professor Patsy Yates, Ms Gillian Batt, Ms Rita Evans and Ms Julie Mueller.

We wish to thank all consumers of Cancer Australia's national advisory and reference groups, and workshop participants, for their valuable comments and feedback.

Our thanks also go to Dr Ian Roos and Ms Tina Thomas for their contribution.

Finally, we gratefully acknowledge the resources and information provided by a range of institutions and organisations including: Cancer Voices, Australian Institute of Health and Welfare, Consumers Health Forum of Australia, Mental Health Council of Australia, Medicines Australia, Adelaide Central Community Health Service, Manitoba Centre for Health Policy and Cancer Councils.

Preface

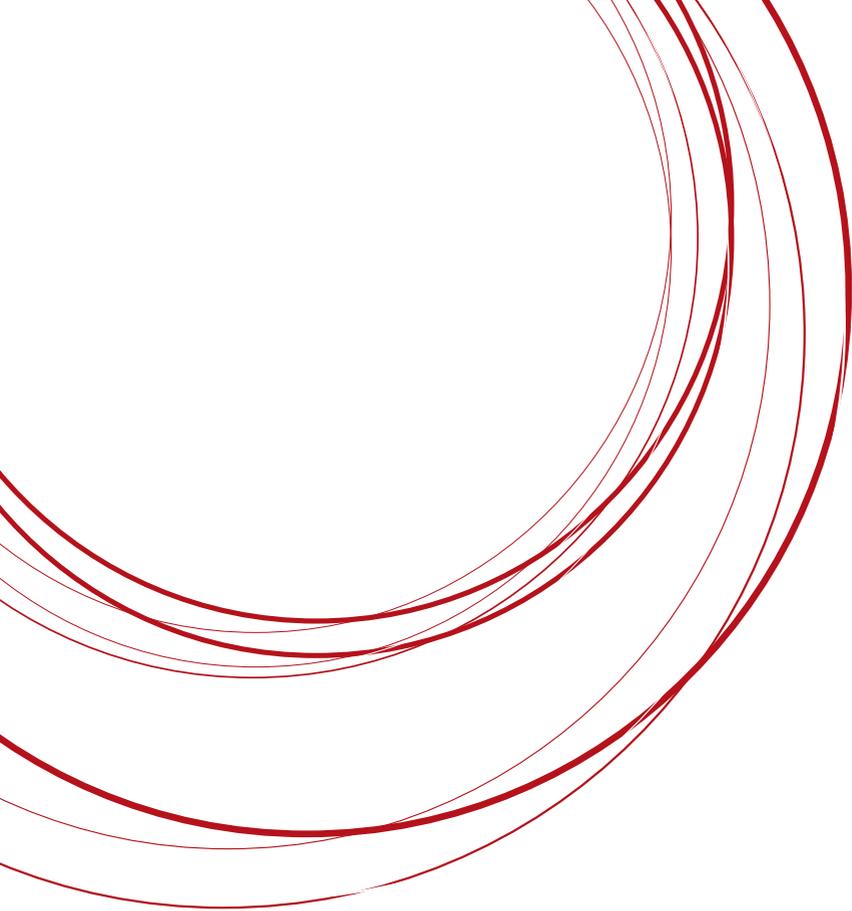
A key component of Cancer Australia's work is to enable consumers affected by cancer to support each other better.

This booklet is one of three resources that have been developed in response to a need to ensure that community support networks meet essential quality and safety standards, and that support networks are accessible, well coordinated and sustainable.

Cancer Australia did not want to duplicate existing resources. We therefore contracted the Health Issues Centre to work in collaboration with key stakeholders to identify the resources required to assist those who support people affected by cancer, and to develop resources to address those gaps.

Following consultation across Australia and an extensive literature search, the Health Issues Centre found that the Cancer Council NSW resource *Cancer support groups: A guide to setting up and maintaining a group* was an extensively used guide that should be promoted nationally as an excellent resource for people wanting to establish a cancer support group. The review and consultation process also showed that there were limited resources to guide peer facilitators to establish and manage cancer support groups. It was also identified that two further national resources would be useful to complement this resource—a resource describing the principles for people wanting to establish a quality peer support group and a resource designed to provide skills to peer facilitators involved in support groups or networks.

This booklet has been produced by Cancer Australia to provide information about the skills required for people who are facilitating a peer support group. It is not intended as a substitute for professional support, and it is not a substitute for participating in professionally run facilitation and leadership training. An accompanying booklet, *Cancer support groups: A guide to setting up a peer supports*, has also been developed by Cancer Australia to specifically address the needs of people affected by cancer who want to establish a peer support group for other people also affected by cancer. Both resource booklets are available from Cancer Australia's website at www.canceraustralia.gov.au



Introduction

A peer facilitator is a person who has experienced cancer, either as a cancer survivor or a carer or family member of a person affected by cancer, who now wants to facilitate a cancer support group for people who have also been affected by cancer.

Research has found that support groups for people with cancer are very beneficial (Herron 2005). However, research has also found that if they are not led effectively, support can be detrimental (Helgeson et al 2001, Cunningham 2000). People facilitating a support group, network or other option also need the assistance of experienced people or organisations. There is no simple way of setting up and running a cancer support group, or other support option, because the illness is so complex—physically and emotionally.

How to use this guide

In this guide you will find information about the qualities and skills (competencies) of a successful support group facilitator. These qualities are useful for facilitating groups that meet face-to-face, over the phone, or online.

The guide briefly introduces a number of competencies for facilitators. These are followed with explanations and examples of each one, presented in the form of short stories. Some of the stories give positive examples of facilitation and others present negative examples. The difference will be clarified in the text. Though fictional, the stories are based on available literature and the experiences of many people who contributed to this guide. Further reading, references and useful links for facilitators have been included to help interested readers continue their learning journey.

Each of the competencies outlined in this guide is recognised by the literature as being fundamental to effective facilitation. There is no such thing as the perfect facilitator, but the most effective facilitators are those who know that the process is a journey, and that they will learn along the way. One of the most effective skills any facilitator can have is to recognise when to ask for help. Finding other facilitators to link and share ideas with, and seek support from, is an important part of your own development and a wonderful way of getting the positive feedback you deserve.

If you decide to go ahead and establish a cancer support group, or if you are already involved in a group, the following resources will also help you:

- ▶ *Cancer support groups: A guide to setting up peer facilitated supports* (produced by Cancer Australia), which specifically addresses the needs of people affected by cancer who want to establish a peer support group for other people affected by cancer. This resource is available from Cancer Australia's website at www.canceraustralia.gov.au
- ▶ *Cancer support groups: A guide to setting up and maintaining a group* (produced by the Cancer Council NSW), which is an easy-to-use and practical guide to setting up and maintaining a support group. It is mainly aimed at groups that focus on providing support and information. This resource is available from the Cancer Council New South Wales website at www.cancercouncil.com.au. A number of Cancer Councils in other states have also modified this resource to reflect their state or territory services.

Summary of competencies for effective facilitators

The competencies are illustrated by examples of how they work in a group setting:

Balance

Awareness of self, balanced with awareness of the group

Tasks and activities of the group, balanced with the wellbeing of the group

Empathy

Listen more than speak

Aim to understand each perspective and hold each person in positive regard

Be willing to let old assumptions go on the basis of new information

Flexibility

The group is more important than the agenda

Some days things work, some days they don't

Use the suggestions others make

Impartiality

The facilitator is doing the group's work, not the other way around

The goals and outcomes are determined by the group, not the facilitator

The facilitator guides the group, but doesn't control it

Focus on process

How things are done is as important as what is done

If it's not working, do it another way

Intuition

Trust the process

Trust the group

Trust yourself

Inclusion

Everyone's input is important

Everyone has a story to tell

Everyone can learn something from others

Creativity

Try new ways

Experiment with new ideas

Look at things from different perspectives

Humour

Appropriately lighten the mood when the work is hard

Laugh at yourself

Laugh WITH the group but never AT anyone

Explanations and examples

Balance

The role of the facilitator is a complex balance between awareness of self and consideration for the interests of the group. If the emphasis is too much on self, then the needs of the group will suffer.

The facilitator's role is complex and at times lonely, so it is a very good idea to share the facilitation with another person (cofacilitator). You can support each other during and after sessions. While one is busy organising activities or facilitating discussions, the other can be observing individuals and noting body language and other indications of discomfort or distress.

Debriefing (reviewing processes or events) and getting things off your chest are also very important for maintaining balance. Where possible this is best done with a professional, such as a social worker or psychologist. Facilitation is also enhanced with regular reflection—thinking about what is working well and building on that, as well as taking on board the feedback that others have given you and finding new and better ways to work with the group.

CASE STUDY

Marisella was lucky. She survived her cancer and is passionate about sharing her story and supporting others with the same kind of cancer. Marisella sets up a support group that starts off well, but members soon stop coming. Before leaving one member thanks Marisella for her enthusiasm and passion but admits that with her cancer in its advanced stages, the messages of hope aren't helping her.

Marisella's intentions were wonderful but her focus was on herself and her story rather than on the group. Facilitators are not effective when driven by their own agendas, no matter how well meaning they are.

CASE STUDY

Pauline survived her cancer and in the process realised how important unconditional support had been to her recovery. She starts a support group for people with similar cancer. Pauline's group provides many different kinds of support and is driven by the needs of the people who attend. Pauline listens and feeds her understanding back to the person speaking. She reminds the group of what the agreed purpose is when it looks like it is going off track. When a member of the group dies, Pauline knows it is time to get some professional support to help her and the group deal with their grief.

Pauline has had a life-changing experience but she is not trying to change other people's lives because of it. She is using her experience to support the people in the group to meet their goals. Pauline knows her own limitations, so when the group is faced with a great challenge, she calls for help.

Facilitation is more than just a set of skills. Of course, there are some wonderful skills that facilitators use to great effect, but being able to pull activities and games out of a hat is not going to work if the group needs something else.

CASE STUDY

Paul has very little experience as a facilitator. He decides to attend a weekend course on facilitation he saw advertised in the local paper. After the weekend, he is really excited about trying out some of what he has learnt on his support group. At their next meeting he tells them about a great process he has learnt and encourages the group to try it out. The process encourages people to share at a very deep level. One person becomes very emotional during the activity and the intensity upsets the rest of the group. Paul does not know how to deal with what is happening.

Some processes and activities can be quite confronting for individuals and the group, as the example above illustrates. Using processes such as these takes a lot of skill and a great deal of practice. Trying out a new process on a group should be done with caution, especially if it has the potential to release strong emotions. One way is to tell the participants what the new process is, and what it could potentially do, and let them decide whether to

go ahead or not. When trying something new, keep a close eye on the group and if you have any concerns, stop the process. Other processes or activities may be appropriate in one setting but not in another, and knowing when to use them is a skill in itself.

Becoming an accomplished facilitator takes time and practice, and it is not a role that suits everyone. Because facilitation is so different to leadership, strong leaders do not always make good facilitators.

So what is the difference between leadership and facilitation?

In a group setting, the two roles can be completely different and undertaken by different people. For instance, if the group is in difficulty, a person may take a leadership role by suggesting a solution and offering to implement it. The leader in this case is also willing to take responsibility if things go wrong. Leaders are often assertive, articulate and perceived as strong. Facilitators take the group pulse and work with the group to resolve difficulties. They help the group find a way forward and are not usually the people who take action—this is usually done by one or more of the other people in the group. Sometimes a facilitator can take a leadership role and assertively suggest a way forward, but this should only happen if the group has run out of options.

CASE STUDY

Mario is the chair of many committees and the local hospital board. He has years of experience in this role. When he is diagnosed with cancer he starts a support group and takes on the role of leader. Mario sets the agenda, calls for votes when the group is divided on an issue, introduces all the speakers and generally runs the sessions like formal meetings, making all the decisions for the group. Before long, people have left the group. One person tells him that they were not given the opportunity to contribute in a meaningful way, and that in a support group they didn't expect such formality.

Everyone in the group needs the opportunity to participate, and to take on roles if that is what they want to do. Many are happy to take no role at all, but others enjoy the challenge. An effective facilitator will encourage group members to share the facilitation and other roles so that the skills are passed along, while making sure that the group stays true to its purpose—support—and does not become a formal meeting.

Empathy

Empathy is an important quality, or skill, for a facilitator. Showing an understanding of what the group and its individuals are feeling is an essential component to helping the group reach its goals.

CASE STUDY

In his support group, Tan shares that he is finding it hard to talk to his teenage children about his cancer and what it might mean for them. Every time he tries to discuss it with his children, they change the subject or leave the room. The facilitator, Anton, leans towards Tan and says, "It sounds like you are having a really hard time talking to them". Tan nods. Anton goes on, "It's hard enough raising teenagers without adding cancer to the mix". Tan agrees and soon the group is discussing ways in which they have approached this issue with their children.

Empathy is attempting to understand the perspective of another, for which the main tool is listening. Carefully prompting the speaker with questions may help to explore the territory.

Facilitators are allowed to make mistakes and get things wrong. They are human after all. Because they are not 'leaders' in the traditional sense, maintaining the perception of strength and invincibility is not essential. The facilitator, not being perfect, can often provide reassurance for the group. The next story illustrates this well.

CASE STUDY

Carmen has facilitated an online bowel cancer group for two years. Coming from a medical background she is sceptical of complementary therapies. When Andrew joins the group and shares his belief in complementary therapies, Carmen is dismissive, saying that the group preferred to concentrate on evidence-based information. Andrew replies to Carmen that not only does he believe in complementary therapies, but he is also an accredited acupuncturist. Carmen apologises to Andrew in front of the whole group and encourages him to share some of his knowledge about the benefits of acupuncture for the management of distressing symptoms. The group report that they really enjoyed Andrew's information and appreciated not only that Carmen admitted she made a mistake, but was willing to open her mind to other possibilities.

Flexibility

Things change. That is the only certainty when working with groups of people. Flexibility is one of the most important skills a facilitator will need. Flexibility extends to just about every aspect of the facilitation role—preparing and operating in the physical (or virtual) environment, organising events and speakers, making decisions and solving problems. A good facilitator responds to change with a positive outlook and creativity.

CASE STUDY

Tim and the group he facilitates have organised for a guest speaker to attend their meeting. The speaker arrives with his PowerPoint presentation and is getting set up, ready to start. Huang arrives shortly afterwards and immediately Tim sees that something is wrong. Huang shares that he had some poor test results today. The focus of the group turns to supporting Huang, and Tim takes the guest speaker aside. They both agree that he should reschedule the talk for another time.

Tim saw that Huang's needs were the most immediate, even though a speaker was already present and ready to start. Supporting the group's needs is the key outcome of the group, and must always remain its priority.

Tim and the group were flexible and compassionate which allowed Huang's needs to be met.

Impartiality

Impartiality means not favouring any individual or group. This is one of the hardest skills for a facilitator to apply consistently. The difference between a leader and a facilitator is that the facilitator knows they must not use their power and influence on the group and, hopefully, they are self-aware enough to notice if this is starting to happen.

CASE STUDY

Bonnie is taking her turn to facilitate the group. After the guest speaker has finished and left, the group is meeting to decide on the program for the next six months. Some of the group suggest having fewer social activities and more information sessions. Other members in the group join in the discussion and appear to be persuaded by the argument. Bonnie, who is very keen on the social aspects, reminds the group they are running out of time and shuts down the conversation, moving it onto selecting guest speakers. At the end of the session she states that no decisions were taken to change the format of the group so things will go on as usual.

The facilitator's role is to enable and support the group in its decisions; therefore, the facilitator must not promote their own opinions and preferences.

Focus on process

Maintaining a balance between what is done and how it is done is another skill an effective facilitator needs to develop. Another way of thinking about it is the difference between the task of the group (what it is there to do) and the maintenance of the group (how it looks after the people in the group). Groups work best when the 'what' and the 'how' are evenly balanced. If the group has some hard work to do, it should be followed by some 'down' time, or by presenting the work in such a way that it is enjoyable rather than a chore.

Facilitators use many different processes to engage the group. Many websites give ideas that can be applied in many different settings (see ‘References and further information’ at the end of this resource). You can also contact your local library, which may have a range of print and audio-visual resources you can borrow.

In thinking about process, the facilitator needs to be constantly aware of what would engage most group members, what would be the most effective way of presenting information and how each person’s needs can be balanced with the overall need of the group. This must be done while always bearing in mind that the processes must be appropriate in a cancer support setting. Processes are not tricks or games—they are well-planned ways of working with the group to advance the goals of the group, and to engage the people in it.

CASE STUDY

Ali has noticed over the past few sessions that Janet and Karen say very little. The sessions are usually dominated by Pat and Sylvia. At the next session, Ali breaks the group into three smaller groups and makes sure that Pat and Sylvia are together in one group and Janet and Karen together in another group. He tells each small group that only one person can report back. When it is time to report back, it is clear that Janet and Karen’s group have had a lot to say. Ali is very pleased to see that Janet offered to be the reporter.

This very simple process allowed two people who seldom spoke to participate in a way that was less threatening to them. At the same time the people who often speak were still able to have their say without dominating. That is not to say that the problem may not reappear at a later date. The facilitator needs to be alert to this happening, and, if necessary, involve the whole group in solving the issue.

Intuition

Facilitation literature often mentions intuition as an important component of the facilitator's role (Thomas 2007). Simply put, it means going ahead and acting even though at times you may not know why you know. The caution, according to Thomas, is to always test your assumptions with the group and to do this tentatively.

Develop trust in the group by constantly running your thoughts or perceptions past them. If you are wrong, they will tell you. If you try and cover up mistakes they will notice. Trust the process. This can be very hard when things appear to be going wrong. Sometimes things need to go through a confused or rocky period to get to where they need to go.

CASE STUDY

The Royston Cancer Support Group is in trouble. Members have been leaving, saying their needs are not being met and the group has virtually divided into two opposing camps over how it should be run. Holly is facilitating a session to resolve the issues. For half an hour both sides have their say, with Holly making sure people are respectful but otherwise just letting them 'get it out'. After half an hour she sums up the main differences that she has noticed and asks the group whether or not they agree. They do. She then suggests they brainstorm ways they can work together. To begin with, people suggest solutions that will only work for their 'side', but with prompting from Holly, they gradually start seeing other alternatives. It is hard work but in the end the group reaches agreement.

Holly might have been tempted to shut down the discussion because people were not agreeing, but she trusted the process. She knows there are times when people just need to say what is on their mind and, provided they do it with respect, no-one gets hurt (or so she hopes). She trusts that everyone in the group wants to resolve the issue so she persists through the negativity. Eventually her persistence and trust in the process (and the group) is rewarded.

Inclusion

Everyone has something valuable to offer and everyone has a story to tell. The facilitator's role is to make sure a safe space is created in every group for people to contribute. Many people are uncomfortable talking in front of a big group. The example where Ali breaks the group into smaller groups is one way of allowing quieter people to participate (see Focus on process, page 10).

However, it is not always about shyness or uncertainty. In some cultures people are less likely to put their individual ideas forward. If the group includes people from other cultures, find out as much as possible about their culture. The best source of this information is the person themselves (see more on how to include people affected by cancer from specific population groups in *Cancer support groups: A guide to setting up peer facilitated supports*, available from Cancer Australia).

CASE STUDY

Laima is new to the group. She speaks very little English. Bob is facilitating the group, and, before the next session, he finds out some information about Latvia, where Laima is from. He also calls the Cancer Council in his state to find out how he can access an interpreter for Laima.

Participation is not compulsory. Some people may just want to be with the group and are happy to listen to what others are saying. The facilitator can periodically check with the quieter members to see if they want to contribute something, but this should always be done tentatively rather than directly—"there are a few people who have not said anything. Anne? Joe?" Move on quickly if the quieter ones do not want to say anything to avoid embarrassing them.

Everyone in the group can learn something from everyone else. A good facilitator encourages each person to contribute to the best of their ability and to the fullest extent possible.

Creativity

Facilitators are often going to be confronted by uncertainty. Being creative works alongside being flexible as a quality that is essential to develop as a facilitator. Creative facilitation involves finding new ways to do old things, to give people variety and to create interest. It means taking risks and looking at things from a different perspective.

CASE STUDY

Emma's group has been meeting for over a year. During that year they have had a number of different speakers address the group. Each speaker seems to present in the same way—a lecture with PowerPoint slides and PowerPoint handouts for the group. Emma has picked up that the group is getting a bit bored but that they still want the information. She contacts the next guest speaker and asks if it would be acceptable to them to present in a different way. She suggests that the speaker comes without any prepared information and answer the questions that Emma will draw from the group in a short session before the speaker arrives. The session goes very well for both the speaker and the group.

This new way of getting information may not have worked, but Emma was willing to give it a try. If it did not work, she could involve the group in making suggestions how the process could be improved or how they could get information in more interesting ways.

Because facilitation skills are constantly developing, effective facilitators should be constantly finding out from others how to do things differently, or seeking information in books and on the internet. They are experimenting with new processes and learning on the job, and are picking up new ideas and rethinking old ones based on the reactions and feedback of participants.

Humour

Humour is not to be confused with being funny. Not everyone is funny, and being funny isn't always appropriate. But injecting humour into situations is a very effective way of breaking tension and moving people forward, and is yet another skill of the effective facilitator. In fact, research has shown that participants in support groups value humour in a facilitator (Butow et al 2007).

Humour gets the facilitator through the difficult times and helps to bring things back into perspective. Laughing at oneself is almost mandatory when facilitating. So is laughing with people, but NEVER at them. Because cancer support groups deal with death and dying, the facilitator needs to tread a very fine line between being overly serious and indulging in black humour. The group is the best guide to what is or is not appropriate.

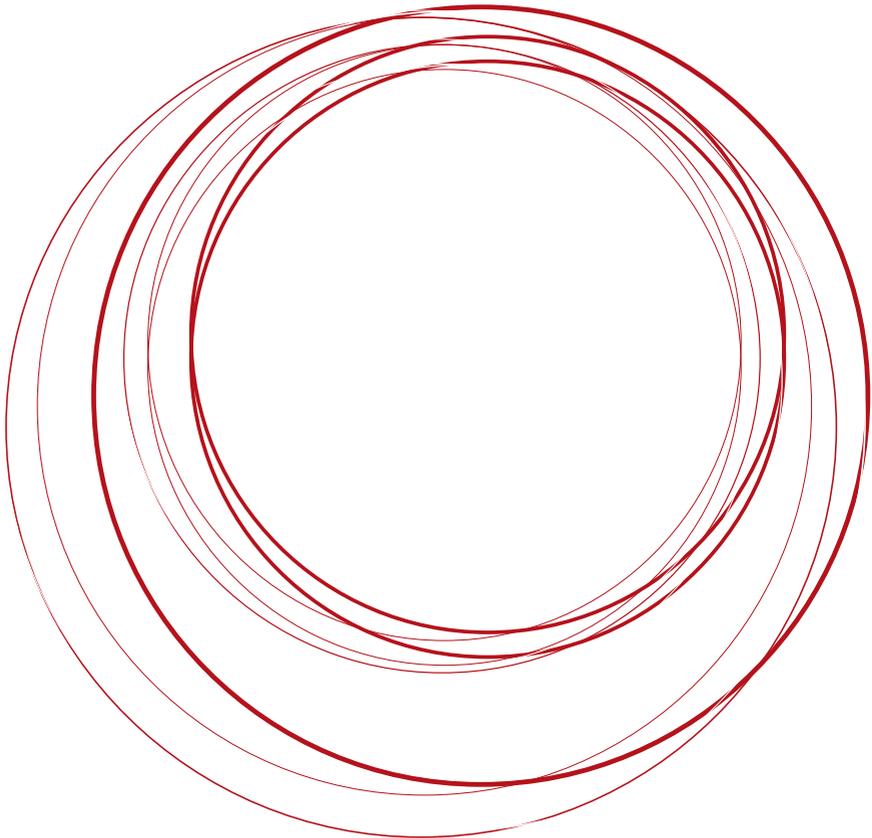
CASE STUDY

Things were not going right for Jack. The guest speaker did not turn up, it was his turn to bring the biscuits and he forgot them, and he called Jane 'June', and she was clearly not amused. Because the speaker had not turned up he suggested the group break into smaller groups for a structured discussion but people seemed to lack enthusiasm for the suggestion. Jack looked around the circle of people for inspiration, shrugged his shoulders and slumped down in his chair with a big sigh. His theatrics caused the group to laugh and once this happened they seemed more ready to discuss how to spend the rest of the session.

Jack had to be careful that he did not do anything too outrageous that might shock the group or make him look too silly. His small gesture worked well and broke the tension in the group. Even in very serious situations, people can appreciate a bit of light-heartedness to lift the mood. This should be done with extreme sensitivity and awareness.

In conclusion

To make sure that supporting people effectively and appropriately is the primary consideration, the facilitator needs to constantly and consistently review what they are doing. A facilitator can never be too skilled or too experienced! Each one should be updating skills through discussions with other facilitators, support from a supervisor and through accessing other resources like books, websites, and face-to-face and online groups. Whenever possible, working with a cofacilitator should always be the aim. Facilitating a support group is a challenging role, and sharing the load is good both for the facilitator and for the group.



References and further information

Butow PN, Kirsten LT, Usher JM, Gerard VW, Sandoval M, Hobbs K, Hodgkinson K and Stenlake A (2007). What is the ideal support group? Views of Australian people with cancer and their carers. *Psycho-Oncology*, 16(11):1039–1045.

Cunningham AJ (2000). Adjuvant psychological therapy for cancer patients: Putting in on the same footing as adjunctive medical therapies. *Psycho-Oncology* 9:367–371.

Helgeson VS, Cohen S, Schulz R, Yasko J (2001). Long-term effects of educational and peer discussion group interventions on adjustment to breast cancer. *Health Psychol* 20:387–392.

Herron L-M (2005). *Building effective cancer support groups*. Report to the Department of Health and Ageing, The Cancer Council Australia, November 2005.

Tips for facilitators

Lyme Disease Foundation (2007). Organizing & conducting a self-help group, *Facilitator panic button manual*, online text.
www.lyme.org/education/self-help/facilitator-panic.html
(Viewed by author 30 Jan 2008)

Tips for working with diverse groups

The Thiagi Group (2007). *Intercultural insights: List of guidelines*, online text.
www.thiagi.com/email-intercultural101-tips.html
(Viewed by author 31 Jan 2008)

Further reading

CAP Santé Outaouais (2007). *Facilitating the self-help group*, online text. www.capsante-outaouais.org/english/self-help-web/facilitating.html (Viewed by author 30 Jan 2008)

InterAct Networks. *Facilitator competencies—an evaluation framework for facilitators*, continual draft, online text. www.interactnetworks.co.uk/documents/InterAct-INCompetencies4.pdf (Viewed by author 31 Jan 2008)

McFadzean E (2002). Developing and supporting creative problem solving teams: Part 2—facilitator competencies. *Management Decision* 40(5/6): 537–551.

Thomas G (in press). *Facilitation Education, Theory and Practice*, La Trobe University, Bendigo Campus.

